

# Physician Communication in Pediatric End-of-Life Care: A Simulation Study

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## Abstract

**Objective:** The objective of this exploratory study is to describe communication between physicians and the actor parent of a standardized 8-year-old patient in respiratory distress who was nearing the end of life. **Methods:** Thirteen pediatric emergency medicine and pediatric critical care fellows and attendings participated in a high-fidelity simulation to assess physician communication with an actor-parent. **Results:** Fifteen percent of the participants decided not to initiate life-sustaining technology (intubation), and 23% of participants offered alternatives to life-sustaining care, such as comfort measures. Although 92% of the participants initiated an end-of-life conversation, the quality of that discussion varied widely. **Conclusion:** Findings indicate that effective physician–parent communication may not consistently occur in cases involving the treatment of pediatric patients at the end of life in emergency and critical care units. **Practice Implications:** The findings in this study, particularly that physician–parent end-of-life communication is often unclear and that alternatives to life-sustaining technology are often not offered, suggest that physicians need more training in both communication and end-of-life care.

## Keywords

pediatric end-of-life care, end-of-life communication, physician–parent communication, simulation, qualitative methods

## Introduction

Among parents of children who are approaching the end of life, interactions with health care providers are consistently regarded as the most important factor in their overall evaluation of their child’s health care experience.<sup>1-3</sup> This makes quality communication between parents and clinicians paramount in the care of children with life-limiting conditions.<sup>4-7</sup> The way information is relayed, the truthfulness of communication, and the timing of discussions are crucial to ensure that children who are nearing the end of life are provided with the most appropriate care possible. Often such communication includes comfort care as opposed to life-sustaining measures.<sup>5,7-10</sup>

Over a decade ago, the Institute of Medicine (IOM)<sup>11(p358)</sup> called on researchers to “combine creativity, flexibility, and sensitivity both to patient and family burdens and anxiety” in efforts to examine end-of-life communication with parents. Since that time, many studies have examined parents’ perspectives on their experiences.<sup>8,9,12-17</sup> However, few studies have directly examined the process of physician–parent end-of-life communication.<sup>18</sup> Simulation may be a particularly useful tool in observing this type of communication because utilizing real-life settings is difficult due to logistical and ethical issues related to gaining access and studying a rarely occurring, exceedingly emotional phenomenon. Findings emerging from this type of research would provide important insight into the

quality of communication that occurs between physicians and parents of children at the end of life, which would ideally lead to recommendations for training that could improve physician–parent communication.

This exploratory study aims to utilize high-fidelity simulation to describe communication between physician participants and the actor parent of a standardized 8-year-old patient in respiratory distress who is nearing the end of life. To our knowledge, this is the first attempt to combine the use of qualitative research methods with high-fidelity pediatric simulation to better understand communication related to end-of-life care. We use the IOM’s definition of end-of-life care as that

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which “focuses on preparing for an anticipated death . . . and managing the end stage of a fatal medical condition.”<sup>11(p2)</sup>

## Methods

### Participants

Thirteen pediatric emergency medicine (PEM) and pediatric critical care (PCC) fellows and attendings were recruited via e-mail to participate in a high-fidelity simulation followed by a semistructured debriefing interview. All participants practiced at a single, 380-bed academic children’s medical center in the southeast. These 2 specialties were chosen because they are similar in that they see patients for relatively short periods of time, and patients almost always present with the goal of recovery. Although it is certainly true that often physicians in the pediatric intensive care unit (PICU) may have more time to develop relationships with patients than those in the pediatric emergency department (PED), the nature of care in the current era is that there are often multiple handoffs, physicians on call for short periods of time, and acute changes in patient status that would place both emergency medicine and critical care physicians in the type of scenario where neither has had the time nor opportunity to build rapport with the patient and their family.

### Data Collection and Analysis

Data collection took place between August 2011 and March 2012. The study protocol was approved by the institutional review board (IRB) for Human Use at the University of Alabama at Birmingham. Simulations were designed to assess physicians’ decision making and communication with the actor-parent of a standardized 8-year-old patient in respiratory distress who was nearing the end of life. High-fidelity simulation has become a common tool for both the education and the evaluation of clinical providers during all levels of practice.<sup>19-22</sup> In high-fidelity simulations, a mannequin takes the place of a patient and an instructor controls the mannequin’s clinical signs and symptoms, such as vocal, heart, and lung sounds; observable and palpable signs; and physiological changes through a computer connection.<sup>23,24</sup>

Studies indicate that simulation can be a reliable and valid method for evaluating clinical competence<sup>22,25</sup> and that in addition to clinical skills, physician–patient communication can also be observed and evaluated.<sup>24,26,27</sup> Simulation may be a particularly useful tool in examining end-of-life communication between parents of dying child patients and PCC and PEM physicians because the emotional milieu of both the PICU and PED and the infrequency of these discussions renders it difficult for a researcher to gain access to observe communication first hand.

Potential participants were told that the study was assessing medical decision making in PCC. When the participant presented to the Simulation Center, he or she was given an informed consent document approved by the IRB and given the

option to sign. Each was then given a written medical history (Appendix A) of a simulated 8-year-old patient which indicated the patient was nearing the end of life, in that she had been intubated 3 times in the previous 4 months for respiratory distress related to a fictitious progressive neurological disorder. Before the participant entered the simulation, he or she was told by the facilitator (either the Medical Director or Medical Co-Director of the Simulation Center) that the patient had just presented to the PED. The simulation included a child mannequin and a trained actor-mother who followed a script (Appendix B) that contained the child’s medical history. Two sociology graduate students were trained extensively to serve as the actor-mother. Simulations were audio- and video-recorded.

The child mannequin’s initial vital signs showed respiratory failure with low levels of oxygen circulating in her blood. Her oxygen levels increased to normal when oxygen therapy was applied. As the simulation progressed, the vital signs were manipulated in such a way that the physician was compelled to decide whether or not to intubate the child. The simulation session was stopped when the participant indicated that he or she made a decision about whether or not to intubate. Each simulation session was followed by a postsimulation semistructured debriefing interview, which was audio-recorded and transcribed. After the interview, participants were asked to complete a demographic questionnaire.

Simulation and postsimulation interview audio recordings were transcribed by the first author (LBB) and an assistant and then coded in 2 phases by LBB, under the supervision of her mentor, JMC, as part of her dissertation. Atlas.ti version 7.0 was utilized to facilitate the coding and analysis process.

In the initial coding phase, each line of data was named and then the most significant and/or frequent codes were used to sort, synthesize, and integrate the data.<sup>28</sup> In the next, focused coding phase, recurrent concepts were arranged into codes that are more “directive, selective, and conceptual” than initial coding.<sup>28</sup> These codes classified the data according to emerging themes based on the participants’ responses. Throughout the coding process, codes were deleted, trimmed, renamed, and merged into larger categories that corresponded with themes in the data. These themes were recorded in the form of theoretical memos, written throughout the coding process. Although we followed the tenets of grounded theory during this initial coding process of the open-ended postsimulation interview, those data are considered preliminary.

The data from the simulation study led us to propose an additional phase of the research, which consisted of individual narrative interviews with the participants to further explore emerging themes. Likewise, the emerging data from the narrative interview study led us to propose a second round of interviews, which we pursued until we reached data saturation. The findings reported in this article represent the preliminary results from only the simulation portion of the study. The full study, including the developed theory, can be found in the first author’s dissertation.<sup>29</sup> A more concise published description of the grounded theory coding process used is appropriately explicated in Bateman and Clair,<sup>30</sup> which lays out the dynamic

nature of the grounded theory process through all 3 data collection points.

## Results

Demographic characteristics of the sample are presented in Table 1. Eighty-five percent of the participants ultimately intubated the simulated 8-year-old patient who was approaching the end of life. Themes related to physician communication which emerged from the transcript analysis include initiating an end-of-life discussion, inquiring about “doing everything,” inquiring about a previous end-of-life discussion, and offering alternative/comfort measures. A summary of findings can be found in Table 2.

### Initiating an End-of-Life Discussion

All of the participants except 1 (92%) initiated some form of an end-of-life discussion with the parent. The form of that discussion varied between participants, with some participants' communication about end-of-life issues appearing awkward, confusing, or leading. For example, awkward communication can be seen when a male attending physician inquires about the actor-parent's wishes for her daughter: “. . . different people have different feelings about whether or not to do certain interventions in difficult cases and I didn't know if you thought about that before, been thinking about that today.” And, a female attending physician asked, “Have you discussed with your primary doctor her condition in terms of, how it relates to her future and what to expect in terms of the level of sickness . . . how you feel and what these thoughts are in terms of how much you would like the medical professional to do in terms of her resuscitation . . .”

An example of leading communication can be seen by the comment stated by a male attending: “. . . if you've not discussed with the regular doctor if this is beneficial or not [intubation], then it is the right thing for you to do at this point. Are you okay with me doing that?” Another example of a leading inquiry into the parent's agreement with the physician's decision to intubate was given by another male attending: “Let's just go ahead and get her situated [by intubating], okay?”

### Inquiring about “Doing Everything”

The question, can we “do everything to take care of her,” was asked in similar ways by 46% of the participants. For example, 1 male attending physician inquired, “In other words, you want us to take care of her, as much as we need to, up to the maximum things we need to do for her?” And, a female attending physician likewise asked the actor-parent, “And if she gets sick like that again you want us to go ahead and intubate her and do everything we can for her?”

### Offering Alternative/Comfort Measures

Only 23% of the participants suggested alternative, comfort measures and one of those, a male fellow, was clearer in what

**Table 1.** Demographics of Participants.

	N = 13
Sex	
Female	5 (38.5%)
Male	8 (61.5%)
Race/ethnicity	
White	11 (84.6%)
Nonwhite	2 (15.4%)
Specialty	
PEM	7 (53.8%)
PCC	6 (46.2%)
Rank	
Fellows	4 (30.8%)
Attending	9 (69.2%)
Parental status	
Parent	7 (53.8%)
Nonparent	6 (46.2%)

Abbreviations: PEM, pediatric emergency medicine; PCC, pediatric critical care.

**Table 2.** Analysis of Physician Communication in Simulation: Themes of Responses.

Theme/response	% of participants
Initiating an end-of-life discussion	92
Inquiring about doing everything	46
Inquiring about a previous end-of-life discussion	38
Offering alternative/comfort measures	23

he was offering. This participant, who was 1 of the 2 who did not ultimately intubate the simulated patient, stated, “She will be comfortable and we have an IV in her so we can always give her a little bit of sedation to make sure with this happening, with her CO<sub>2</sub> going up is a very peaceful way to pass away. It is the way that your body naturally does it itself.”

The other participants who mentioned comfort care were not as clear or comprehensive. For example, when a female fellow, the other participant who did not intubate the simulated patient, suggested to the actor-parent that they could “support her as best as we can” as an alternative to intubation, the actor-parent inquired as to what “support her” meant. The participant responded, “More or less just make her comfortable. Oxygen by the face mask.” The participant did not clearly describe what alternative measures to intubation might entail.

## Discussion

The findings in this study indicate that effective physician–parent communication may not consistently occur in cases involving the treatment of end-of-life patients in pediatric emergency and critical care units. Although research is sparse on what constitutes “good” communication in pediatric end-of-life care, the IOM suggests that effective physician–parent end-of-life communication should include, “Complete, timely, understandable information about diagnosis, prognosis, treatments (including their potential benefits and burdens) and palliative

care options; early and continuing discussion of goals and preferences for care that will be honored wherever care is provided; effective and timely prevention, assessment and treatment of physical and psychological symptoms and other distress; and competent, fair, and compassionate clinical management of end-of-life decisions about such interventions as resuscitation and mechanical ventilation.<sup>11(p9)</sup> In this research, we were able to observe and evaluate many of these facets, in particular the clarity of the language, whether or not comfort measures were offered and whether or not parental desires were assessed.

### *Awkward Communication*

This research suggests that end-of-life communication with parents may be awkward for physicians in an emergency setting. Although physicians may resist telling parents painful news about their child's prognosis out of respect for the principle of beneficence, not being truthful may lead to greater pain.<sup>15,31</sup> If communication is closed and directive, then reaching a shared understanding of the problem and course of treatment may be difficult. Further, when communication is directive, parental decision making can be compromised. In the example given previously in which the participant states that intubation is the "right thing" and then asks the actor-parent if she is okay with that decision, it would be difficult for a parent to object to what the physician said was the "right thing."

Parents want their children's physicians to use clear and comprehensible lay language and to provide comprehensive information.<sup>2,8,31-33</sup> Using awkward language may limit the parent's ability to make informed decisions. In the findings presented here, the physicians attempted to elicit the actor-parent's perspective, but their language may have been confusing to a parent. For example, questions such as, can we "do everything to take care of her" (asked by 46% of the participants) may be interpreted by parents to mean that if they decide against life-sustaining technology, they are not adequately taking care of their child. Instead of using the language of "doing everything" when discussing life-sustaining technologies, language could be used which focuses on the relief of suffering as a viable option alongside life-sustaining technologies.

### *Offering Alternative Measures*

In this research, although the simulated pediatric patient was nearing the end of life, only 23% of participants offered alternatives to life-sustaining care, such as comfort measures. However, appropriate care for children with life-threatening conditions includes palliative care, even if it is integrated with curative medicine.<sup>11,34</sup> Even if the best course for this particular situation was life-sustaining technology (intubation), discussion of comfort care options would have been appropriate, and only 23% of the participants included this in their discussion.

### *Assessing Parents' Readiness to Discuss End-of-Life Issues*

Since 77% of the participants did not offer comfort measures as a valid alternative to life-sustaining technology, it may follow that the participants did not think parents were ready to fully discuss end-of-life alternatives. However, research indicates that parents may think about limiting technology before health care providers bring it up with them.<sup>32,35</sup> For example, Meyer et al found that 45% of parents of critically ill children thought about limiting life-sustaining technology before the physician initiated such a discussion.<sup>32</sup> Typically, the physician is the one who initiates the end-of-life discussion, although Garros et al found that in 24% of cases in a pediatric setting, the family raised the issue themselves.<sup>35</sup> Although parents fear death for their child, they also do not want their child to suffer.<sup>11,18,36</sup> A recent study analyzed audio-recordings from conversations between physicians and parents of children nearing the end-of-life and concluded that parents appreciated receiving detailed information and desired to actively participate in the conversation and decision making.<sup>18</sup>

Research shows that physicians may not discuss advanced directives or palliative care in the PED, since physicians in that setting must make decisions quickly, and they often have limited time to discuss complex medical issues, such as options related to the limiting of life-sustaining treatments.<sup>37</sup> Death in the PED is often sudden and tragic, and the traditional doctor-patient relationship has not been established.<sup>38,39</sup> Because patients and parents do not typically have an existing relationship with the physician, discussions about end-of-life issues may seem inappropriate.<sup>39</sup> However, it has been suggested that in some situations, as the case presented in this research, physicians should discuss a patient's impending death with the patient and family and suggest that comfort measures may be the most appropriate form of care.<sup>37,40</sup>

### *Physician Training Needs*

The findings reported here which suggest physicians need more training in pediatric end-of-life communication and care are substantiated in the literature. In one study examining physician's self-reported confidence levels about delivering aspects of palliative care, the researchers found that only 19% of the respondents were "very confident" in their ability to deliver difficult news to children and 27% were very confident to deliver difficult news to children's families.<sup>41</sup> Even in hematology/oncology fellowship programs, a specialty where end-of-life issues frequently emerge, one study found that 92% did not require a rotation in palliative care and 37% did not offer any electives in palliative care.<sup>42</sup> While the accreditation council on Graduate Medical Education now requires that pediatric training programs include formal instruction related to the impact of chronic diseases, terminal conditions, and death on patients and families,<sup>43</sup> residents and fellows still report none to moderate levels of training, experience, knowledge, competence, and comfort in palliative care.<sup>44-46</sup> Physicians who are

better prepared in end-of-life communication would most likely be able to help parents make more appropriate decisions on their children's behalf.

### Limitations

This study has several limitations. First, the use of high-fidelity simulation has limitations; primarily, the extent to which the participant views the simulation as a real-life setting will influence the validity of the results. Other limitations include sample selection. The participants came from only 2 specialties in a single academic institution. And, because this study utilizes a convenience sample of participants recruited electronically, there is the possibility of selection bias in that those who chose to participate may have different characteristics than those who did not choose to participate.

### Conclusion

The findings in this study, particularly that physician parent end-of-life communication is often unclear and that alternatives to life-sustaining technology are often not offered, suggest that physicians need more training in both communication and end-of-life care. These findings are supported in the literature, which indicates that a significant barrier to appropriate end-of-life care for children is the lack of physicians who are trained to offer appropriate communication and care to children nearing the end of the life and their families.<sup>34,36,47</sup>

Future research should explore the reasons why end-of-life conversations do not happen as frequently as optimal and why end-of-life communication tends to be awkward. Researchers should continue to explore the use of high-fidelity, hybrid simulation, combined with qualitative methods, as a methodology for examining physician-parent end-of-life communication. Multisite and multispecialty high-fidelity simulation studies would potentially provide important insight. Furthermore, scenarios such as the one studied here often happen in the presence of an interdisciplinary team rather than with an individual practitioner. Therefore, using simulation with a team of practitioners would yield important results. Ultimately, the goal of these studies would be the development of training interventions to facilitate more effective communication with families of pediatric patients at the end-of-life.

## Appendix A

### Simulation Medical History

**Current situation.** The patient is an 8-year-old girl diagnosed with O'Neil-Needham disease, a progressive neurodegenerative disorder with no cure.

She was brought to the emergency department for fast, noisy breathing. She was bluish around lips. The fast breathing started last night but is much worse now. She has no fever and has not been around anyone who is sick.

**Developmental history.** A normal newborn and infant, the patient has exhibited a steady and relentless decline in physical and cognitive abilities.

She stopped walking at 2 years, lost the ability to speak at 3 years, has been unable to use her hands since the age of 4, and for the past 3 years has been essentially unresponsive.

Her sole means of communication is an expression of discomfort when hungry or when she needs to be changed.

She does not see and no longer responds to sound.

**Feeding history.** She is fed by a gastrostomy tube, placed at 4 years of age.

**Doctors involved.** Dr D., primary care doctor.

Dr M., neurologist, sees her about once per year, or when she is in the hospital. She has seen multiple subspecialists in the past but none actively now.

**Recent past history.** She has been hospitalized 3 times in the past 4 months, each time for respiratory distress.

The last 2 times, she was intubated and placed on a ventilator—the first occasion for 1 week, the second for 4 weeks.

## Appendix B

### Simulation Script for Actor-Parent

**Family history (perspective of mother).** You have no other children, and you provide the majority of care for your daughter.

You prefer not to have your child in school or respite care.

Your husband is supportive but is also the sole means of monetary support for your family. He is your daughter's step father (her father passed away) and he says that he wants you to make the decisions about her care.

There is no family history of a similar disorder.

**O'Neil Needham diagnosis.** A progressive neurodegenerative disease with no known cure. The disease leads to mental retardation, weakness, and loss of the ability to self-care, including feeding. It can cause blindness but usually not deafness.

**Responses for parent.** If doctor asks: "Is your child a DNR?"

Mom answer:

"No," or

"Nobody has really talked to me about that before," or

"My husband and I have been talking about the fact that she keeps getting sick and we really don't understand why."

If doctor asks: "Do you want your child intubated?"

Mom answer: "I don't know. What do you think I should do?"

Doctor replies: "..."

Mom answer: "What do you mean?"

If doctor brings up BIPAP...

Mom says: "She cannot tolerate that. The ICU team keeps trying but the mask never fits and she cannot coordinate with her breathing. Last month the doctors in the ICU team told me to not use it again."

If the doctor suggests that he/she doesn't have to intubate...

Mom answer: “She looks like she’s in pain. If we’re not going to intubate, what can we do?”

*If doctor asks about child’s best interests or parents’ wishes related to end-of-life care . . .*

Mom answer: “I just want her to be comfortable and not in so much pain.”

*If doctor asks if the parent has had a previous end-of-life discussion with a health care provider . . .*

Mom answer: “I don’t remember.”

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